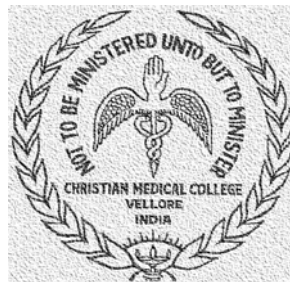


THE INFLUENCE OF MEDICAL AND NON-MEDICAL DETERMINANTS THAT AFFECT LIVING KIDNEY DONOR SELECTION AMONG LIVING-RELATED KIDNEY TRANSPLANT CANDIDATES



A dissertation submitted to the Tamil Nadu Dr. M.G.R. Medical University in partial fulfillment of the University regulations for the award of
D.M. (Branch – III) (Nephrology)



DEPARTMENT OF NEPHROLOGY

CHRISTIAN MEDICAL COLLEGE, VELLORE

BONAFIDE CERTIFICATE

This is to certify that the work presented in this dissertation titled **“THE INFLUENCE OF MEDICAL AND NON-MEDICAL DETERMINANTS THAT AFFECT LIVING KIDNEY DONOR SELECTION AMONG LIVING-RELATED KIDNEY TRANSPLANT CANDIDATES”** done towards fulfillment of the requirements of the **Tamil Nadu Dr. M.G.R. Medical University, Chennai for the D.M. (Branch–III) (Nephrology)** exams to be conducted in July 2009, is a bonafide work of the candidate **Dr. Ilangovan V.**, Senior Post graduate student in the Department of Nephrology, Christian Medical College, Vellore under my guidance and supervision. This dissertation has not been submitted, fully or in part to any other board or University.

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ABSTRACT

ABSTRACT

Aim:

To evaluate the patients with chronic kidney disease stage 5 (CKD 5) and their prospective renal transplant donors regarding:

1. The renal replacement choices made by the patients with CKD 5.
2. To assess the medical and non-medical factors that affect living related renal donor selection among prospective renal transplant recipient.

Methods:

Over 24 months, consecutive patients with CKD 5 and their relatives were interviewed at their presentation to the nephrology services of Christian Medical College, Vellore, and the reasons for the choice of modality chosen were analyzed and the prospective recipient and their donors were again interviewed separately and the medical and non medical factors that affected the donor selection were determined.

Results:

1257 consecutive CKD 5 patients were enrolled over 24 months. Conservative, dialytic treatment and renal transplantation were chosen by 513 (40.8%), 320 (25.5%) and 424 (33.7%) patients. Only socioeconomic status affected significantly the modality chosen and not the age, gender or donor availability. Patients or donor were likely to withdraw from transplant evaluation commonly due to absence of voluntary donor , presence of a male donor, coercion not

to donate and absence of sponsorship either fully or partly. The commonest cause of rejection of a donor was ABO incompatibility (45.8%), followed by diabetes mellitus (DM) or risk of DM (24%), renal disease (5.9%), hypertension (5.5) and persistent cross match positivity (5.1).

Conclusion:

The non medical factors that negatively influences the donor availability or withdrawal should be identified and to improve the rates of organ donation.

INTRODUCTION

Introduction:

The chronic kidney disease is a worldwide public health problem with an increasing incidence and prevalence and hence an increasing number of patient are treated with renal replacement therapy —dialysis or transplantation. The annual incidence of ESRD has doubled over the past decade to reach about 135 per million in Europe and similar rate in USA. It is expected to continue to rise at an annual rate of around 5–8%. In India, the annual incidence is 34–240 per million population³⁸.

Two factors are important. The first is the ageing of the population; the incidence of ESRD is higher in elderly people than in the general population. The second factor is the global epidemic of type 2 diabetes mellitus; the number of people with diabetes worldwide (currently about 154 million) is predicted to double within the next 20 years. And in India as per the diabetes atlas 2006 published by the diabetes federation , the number of diabetes in India currently around 40.9 million is expected to rise to 69.9 million by 2025 unless urgent preventive measures are taken. And with it there is an expected parallel epidemic of diabetic nephropathy.

India currently has approximately 820 nephrologists, 710 hemodialysis units with 2,500 dialysis stations and 4,800+ patients on CAPD. There are approximately 172 transplant centers, two-thirds of which are in south India and mostly privately run. Nearly 3,500 transplants are done annually, the total number of cadaver donors being approximately 700 till now. Thus, taken together, nearly 18,000–20,000 patients (10% of new ESRD cases) in India get renal replacement therapy. The cost of single hemodialysis varies between Rs. 750 and Rs. 2000 with an additional cost of erythropoietin being Rs.6000 - 8000/month. The cost of CAPD using a ‘Y’ set with 3 exchanges/week is Rs. 16000/month. The cost of the transplant procedure in a state-run hospital is Rs. 40,000–

50,000, and the cost of immunosuppression using tacrolimus, steroid and mycophenolate is Rs.15,000–18000/month³⁹.

The number of patients with ESRD probably underestimates the entire burden of CKD because the numbers with earlier stages of disease (stages 1 to 4) are likely to exceed by as much as 50 times those reaching ESRD (stage 5). In the last two decades there has been an increasing evidence that the adverse outcomes of CKD like cardiovascular disease, premature death can be prevented or delayed. Earlier stages of CKD can be detected only through periodic health check ups and laboratory testing. Treatment at earlier stages of CKD is effective in retarding the progression towards stage 5. Unfortunately, CKD is underdiagnosed and undertreated resulting in lost opportunities of prevention.

In 2004 poor Indians spent 40 percent of their income on health care; the rich spent about 2.4 %. Studies have shown that medical expenses were one of the three main factors pushing people into poverty³⁷.

Data from India on the factors that determine the donor selection is lacking. This study was an effort to explore the medical factors and non medical factors that affect donor selection. The non medical factors are amenable to change as against the medical factors. So this study would form a background to see the magnitude of the problem and insights into the non medical factors that affect donor selection.

REVIEW OF LTERATURE

Introduction:

Chronic Kidney Disease (CKD) is a worldwide problem health problem. According to the World Health Organization Global Burden of Disease project, diseases of kidney and urinary tract contribute to 850,000 per year and 15,010,107 disability adjusted life years. This is grossly an underestimate and an unknown number of patient dying with heart disease may in fact have CKD as it is a known risk factor for progression of coronary artery disease.

Indian Scenario:

Incidence and Prevalence of CKD:

Even in rural India chronic non communicable disease are emerging as the leading cause of mortality. There are only three community based CKD prevalence studies in the country¹. The CKD prevention study based on urinary abnormalities and who responded to a questionnaire from rural areas around Chennai showed a prevalence of 0.86% in the study population and 1.36% in the control population². In an urban study from Delhi the CKD prevalence based on a serum creatinine level of 1.8mg% or higher the prevalence was 0.79% or 7852 per million population³. The only longitudinal study that gave an estimate of the incidence of CKD, stage 5 was done in Bhopal; an urban centre gave an average crude incidence of 151 per million population⁴.

Availability of Renal Replacement Therapy:

The widening gap between the need and availability of organ for transplantation is all too familiar. From 1988 to 1997, the number of people waiting for kidneys in the United States almost tripled, while the number of transplants increased by only 36% (a 19% increase in cadaver transplants and a 102% increase in living-donor transplants).

The magnitude of the problem is much greater in India, where about 80,000 people reach end-stage renal disease (ESRD) annually and only 2000 receive transplants and the other 78,000 die⁵. As per an estimate in India 3,500 have renal transplantation done, 15,000 are started on maintenance hemodialysis and 3,000 are started on continuous ambulatory peritoneal dialysis in a year and nearly 21,500 patients, i.e., only 10% of new ESRD cases get RRT⁶.

The mean age of patients entering ESRD programs in the India is much lower (42 years) as compared to the West (61 years)⁷. Therefore, ESRD affects patients in the most productive years of their lives, and these patients are often the sole wage earners of their families. The lower mean age of patients with ESRD at least could be explained in part by the delay in diagnosis and failure to institute strategies delaying progression of chronic renal failure (CRF) to ESRD, and by the lower frequency of diabetic nephropathy due to type 2 diabetes mellitus.

Patients with CRF generally present late in the course of their disease, with 66% patients first seeing a nephrologist when they are already in ESRD. Although in the developed and industrialized world, access to renal replacement therapy (RRT) is unrestricted and easily available, patients in India have to travel long distances to reach a kidney center because of misdistribution of renal services in India, with most of the centers being located in large cities. Furthermore, because of the virtual absence of health insurance plans, less than 10% of all patients with ESRD receive any kind of RRT. Most patients entering RRT programs in the country are funded by their employers or by charity organizations. In a study from a private sector hospital in south India, 63% patients belonged to this group, 30% arranged finances for their treatment by selling property, 20% raised loans and only 4% were able to take care of their treatment costs solely by pooling in family re-sources⁸.

Renal Transplantation in India:

Joseph Murray and his colleagues performed the first successful renal transplant in 1954. As immunosuppressive therapy developed, it became clear that transplantation could be performed on a large scale.

There are approximately 45 major centers (0.05 pmp) performing transplants in India doing an estimated 3000 transplants per year. Living related donors constitute 30 to 40% of all kidney donors in India. The type of kidney donors in a state funded, living-

related kidney transplant program has provided interesting data on the exploitation of females as donors in the society. In this study, 37% of all donors were mothers and the kidney went mostly to the sons (76%); 29% donors were sisters and 88% of the beneficiaries of these kidneys were brothers. In all 66.4% of the donors belonged to the female sex and 83.2% of all recipients were males, spouse donors (largely wives) account for more than 15% of all donors from within families⁹.

Living donors and Morbidity and Mortality:

The risk of death in donor nephrectomy is 1 in 3200¹⁰. The centers come to terms with the possibility of harming living donors by being highly selective in their acceptance of the donors. The important issues regarding the donor, in addition to medical suitability, are whether the donor understands the risks of nephrectomy and whether the donor freely consents.

Most follow-up studies of living kidney donors find no decrease in long-term survival. A follow-up of 430 Swedish donors between 1964 and 1994 found an 85% survival 15 months to 31 years after donation compared to a predicted 66% in the general population of similar age. The survival advantage was attributed to the selection bias¹¹.

Two concerns have emerged regarding the possibility that donors will develop end-stage renal disease. One is that hyperfiltration in the remaining kidney will lead to focal segmental glomerulosclerosis and renal failure, that is, donation per se will cause

renal failure. The second concern is that donors who develop primary renal disease will progress to renal failure more quickly because they have lower-than-normal renal mass at the onset of the primary renal disease. The latter concern applies particularly to patients with a family history that puts them at risk for renal disease, for example, family members of patients with type II diabetes.

In a recent study by Hassan et al ¹², at a mean follow up duration of 12.2 ± 9.2 years after donation, 85.5% of the subgroup of 255 donors had a GFR of 60 ml per minute per 1.73 m^2 of body surface area or higher, 32.1% had hypertension, and 12.7% had albuminuria. Older age and higher body-mass index, but not a longer time since donation, were associated with both a GFR that was lower than 60 ml per minute per 1.73 m^2 and hypertension. A longer time since donation, however, was independently associated with albuminuria. Most donors had quality-of-life scores that were better than population norms, and the prevalence of coexisting conditions was similar to that among controls from the National Health and Nutrition Examination Survey (NHANES) who were matched for age, sex, race or ethnic group, and body-mass index.

Many follow-up studies conclude that the majority of donors derive a tremendous degree of satisfaction and an increase in self-esteem from their donation. Most donors interviewed viewed their donation as an act of heroism and generosity with which nothing else in their lives compared.

Kidney donation is not without a financial burden, however. Although the medical expenses associated with renal donation are covered by the recipient's insurance, 23.2% of donors in one series of 536 reported financial hardship¹³.

Who should be a living donor?

Early in transplantation the donors were both related and unrelated. The reasons for abandoning the live unrelated donors are multiple. Initially before the cyclosporine era the results of unrelated donors were similar to the results of cadaveric transplantation. Data from the United Network for Organ Sharing (UNOS) registry published in 1995 showed an 85% 3-year survival rate for kidneys from 368 spousal donors, 82% for kidneys from 3368 parental donors, and 70% for 43,341 cadaveric kidneys¹⁴.

Friends as donors usually have been accepted with more reluctance than spouses. But the reluctance of physicians to accept or even encourage friends as donors does not take into account that friends would be less likely to feel pressured to donate than would a family member.

Transplant centers regard the altruistic donor with suspicion. A 1968 survey of 54 transplant centers reported that 50% disapproved of the use of living unrelated donors and only 20% had used them¹⁵.

The concern about psychopathology played a role in the reluctance to use altruistic donors. But the fear that was not substantiated in a study that had follow-up of 18 unrelated donors, including 9 strangers, found no psychological complications or regrets after donation¹⁶.

The paid donor, under the guise of altruism, has been a major factor in renal commerce in India, and laws have been passed there restricting donation to close relatives.

The person who gives consent to be a donor should be competent, willing to donate, free of coercion, medically and psychosocially suitable, fully informed of the risks and benefits as a donor, and fully informed of risks, benefits, and alternative treatment available to recipient. The benefits to both donor and recipient must outweigh the risks associated with the donation and transplantation of the living donor organ. Before donation, the live kidney donor must receive a complete medical and psychosocial evaluation, undergo an appropriate informed consent process, and be capable of understanding the information presented in that process to make a voluntary decision.

Donor exchange:

A significant number of patients are unable to undergo living donor transplant despite the availability of willing and otherwise suitable donors because of ABO incompatibility. Paired donation has been applied successfully in this setting, with excellent results in terms of patient and graft survival. Application of this on a large scale of paired donation programs surely will contribute to increase the chances of transplantation in this subgroup of candidates. However, at present, paired donation has not been able to help the vast majority of these patients¹⁸.

Park et al from Korea had shown that the reasons for participating in the exchange process were ABO incompatibility (75.5%), poor HLA match (13.6%), and positive lymphocyte crossmatch (10.9%)¹⁹.

ABO-incompatible renal transplant:

The early dogma suggesting that ABO incompatibility should be considered an absolute contraindication to living donor kidney transplantation has been challenged successfully in the past 2 decades. However, this strategy exposes patients to an increased risk of early graft loss and a higher rate of acute rejection, as well as to the morbidity inherent to the necessary use of deconditioning protocols.

The first attempt at crossing the ABO barrier was made in 1955 by Hume et al. The initial attempts were complicated by hyperacute rejections. In 1964 Starzl et al reported 3 successful kidney transplants across the ABO barrier before better survival were reported later. With improvements in immunosuppression medications and intensive immunologic monitoring, results of A2 donors into O or B recipients have now reached outcomes equal to that of compatible donors²⁰. Unfortunately, these interesting findings have been able to help only a minority of kidney transplant candidates with available ABO-incompatible living donors.

When compared with a control group of 1,055 patients who underwent a compatible living donor transplant, graft survival rates were statistically better in the compatible donor group during the first 5 years, however, there was no difference beyond this point. Graft survival did not differ based on blood type incompatibility, human leukocyte antigen mismatch, or which calcineurin inhibitor was used²¹.

Commercial renal transplantation:

The arguments given for the ban on commercial transplantation are:

- (1) The donor's choice is not voluntary because he is compelled by circumstances of poverty to donate a kidney.
- (2) Paid donors usually are poor and uneducated, so making them understand the risks is all but impossible.

- (3) Commercial donation will result in the rich having access to organs for transplantation while the poor do not.
- (4) Donors will be exploited by unscrupulous middle-men and doctors. The medical care of both donor and recipient will suffer.
- (5) The poor don't know how to handle the money that comes to them and it will make no permanent difference in their poverty.
- 6) During its entire history, transplantation has relied on the altruism of donors and their families. Commercial donations would change the fundamental character of organ donation and likely would lead to the disappearance of altruistic donors. If any transplants are paid for, all will have to be.

Although the sale of kidneys has been illegal in India since the passage of its Transplantation of Human Organs Act in 1994, donors have been able to convince an authorization committee of their kinship with the recipient after coaching from the broker and the recipient.

In 1990, Thiagarajan and colleagues reported on their experience with 153 living related donors and 303 unrelated donors. At two-year follow-up, graft and patient survival were the same for related and unrelated donors. In the process of evaluation, 72% of potential donors were rejected. Those who had come a long way in the evaluation process were paid a small sum for their trouble¹⁷.

The ongoing negative medical, socioeconomic and emotional impact of renal failure upon patients and their families and the financial incentives for donors appears to be driving the commercialization of organs for transplant. However, research suggests that medical, socioeconomic and emotional outcomes for both recipients and donors are poor. While recipients are exposed to the risks of surgery in poorly equipped unsanitary clinics thereby increasing the risk of infection, donors are, in the main, drawn from the lower socioeconomic groups from developing countries, who do not have access to follow up healthcare, or worse, they are carrying infectious diseases, such as TB, HIV or hepatitis²².

Despite donors being motivated by the opportunity to improve their financial status, research has suggested that there is little or no economic improvement following donation. Indeed, in some cases (86% of those surveyed) the average family income actually declined by as much as one-third after donation²³.

Despite the act of donation having being viewed as a business transaction, there still appears to be a stigma attached to organ donation with one study suggesting that 94% of the donors were unwilling to identify themselves as donors, even to close relatives²⁴.

Health Literacy and Access to Kidney Transplantation

The National Institutes of Health define health literacy as the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” Inadequate health literacy is common, found in one fourth to one third of previously studied populations, and has been linked to poorer health-related knowledge, more health care utilization, and worse outcomes²⁵.

Altruistic Living Donor

The living donor transplant has increased a hundred fold in the last 10 years. Even though the possible increase in the number of the deceased donors can solve the problem of organ availability for donation the living donors will continue to be used due to a variety of reason including better cost effective renal replacement therapy.

Recently, there has been mounting evidence of unexpectedly high rates of survival of kidney grafts from living unrelated donors, despite high degrees of HLA mismatch. These donors include individuals such as spouses, emotionally related individuals, and even altruistic donors. In a survey published in 1994, all adult renal transplant centers in the United States were asked for their views and practices regarding unrelated living kidney donation. Of those responding, the majority would accept either spouses or friends (>60% of responding centers) as donors, but only 15% would even consider using emotionally unrelated altruistic donors²⁶.

The hesitancy to perform this procedure from these unconventional donors arises from a number of concerns. One of the arguments is the appropriate concern for the safety and welfare of the donor, particularly since the donor has a less favorable risk–benefit profile. Since donor nephrectomy is a major surgical procedure, there is no doubt that living organ donation requires the intentional infliction of transient physical harm on these individuals. Barring any obvious medical contraindications to donation, there is no reason to think that the medical risk to an altruistic donor should be any greater than that of the more conventional living donor. Furthermore, the vast majority of donors have excellent long-term survival, at least as good as that of the general population²⁷.

The other major argument against the use of altruistic donors is based on ethical considerations. In some cases, there is concern about the donor's motivation, and that the establishment of using strangers as donors would set transplant medicine on a slippery slope toward commercialism of vital organs. However, there is no reason to believe that the desire to donate an organ to a stranger is necessarily a pathological obsession.

Sadler et al., in a study of 18 unrelated living donors (nine of which were altruistic strangers), found no evidence of psychopathology, and post-hoc, none experienced psychological complications or regret following donation. Secondly, since the offer to donate is being made altruistically, there is a greater likelihood that the patient is truly acting autonomously without external pressure to undergoing the procedure; likewise, it may be argued that these individuals are the only living donors that can truly give an

informed consent, since there is are no overlying emotional concerns or sense of obligation that would invalidate voluntary consent²⁸.

A particularly important influence in the field of altruistic living donation is the work of the German Interdisciplinary Arbeitsgruppe Lebenspende, which was established to investigate in depth, the ethical, legal, psychological, and medical aspects of living organ donation. This group has concluded that, in principle, there are no ethical or medical grounds on which to exclude genetically unrelated living donors; rather, they have emphasized the need for a firm demarcation between acceptable and unacceptable types of living donation, based on reliable models and instruments that can objectively confirm altruistic motivation, genuine voluntariness and absence of coercion²⁹.

This has been incorporated into a prospective clinical trial that involves a series of lengthy interviews involving the potential donor and recipient and a mediating psychologist, leading to the signing of a transplantation contract. It is noteworthy that the German parliament has incorporated aspects of investigators' model into a bill making it unconstitutional to categorically exclude potential unrelated living donors if living donation is contemplated.

Direct and indirect economic costs incurred by living kidney donors:

Despite the many benefits of living donor kidney transplantation, economic consequences can result for donors. While expenditures for medical evaluation, surgery

and hospital care are generally covered through public or private insurance, donors are often responsible for other costs associated with the donation process³⁰.

The Human Organ Transplant Act 1994, India like many other organizations prohibits payment for organs and tissues for donation and transplantation but excludes from the reasonable reimbursement of expenses such as those incurred in procurement, transport, processing, preservation, and implantation from the definition of payment.

The direct cost involved are for travel, accommodation, long distance phone calls, medical expense and the indirect costs involve lost income, hired caregiver cost, and others. Other individuals involved with the process of living kidney donation often experience costs as well. Persons who volunteer to donate, but do not proceed with donation, experience out-of-pocket expenses during the evaluation phase. Also, family members, spouses or friends who support donors by providing accompaniment to the transplant centre and care during convalescence may incur many of the costs that are relevant to donors³¹.

Evaluation of a prospective donor: ³⁷

Acceptable donor renal function

All potential kidney donors should have GFR estimated.

Creatinine-based methods may be used to estimate the GFR; however, creatinine clearance (as calculated from 24-h urine collections) may under or overestimate GFR in patients with normal or near normal renal function.

Calculated GFR values (MDRD and Cockcroft-Gault) are not standardized in this population and may overestimate GFR.

A $\text{GFR} \leq 80 \text{ ml/min}$ or 2 SD below normal (based on age, gender, and BSA corrected to 1.73 per m^2) generally preclude donation.

Hypertension

Patients with a $\text{BP} > 140/90$ by ABPM are generally not acceptable as donors.

BP should preferably be measured by ABPM, particularly among older donors (> 50 years) and/or those with high office BP reading.

Some patients with easily controlled hypertension, who meet other defined criteria, e.g. < 50 years of age, $\text{GFR} > 80 \text{ ml/min}$, and urinary albumin excretion $< 30 \text{ mg/day}$ may represent a low-risk group for development of kidney disease after donation and may be acceptable as kidney donors.

Donors with hypertension should be regularly followed by a physician.

Obesity

Patients with a $\text{BMI} > 35 \text{ kg/m}^2$ should be discouraged from donating, especially when other comorbid conditions are present.

Obese patients should be encouraged to lose weight before kidney donation and should be advised not to donate if they have other associated comorbid conditions.

Obese patients should be informed of both acute and long-term risks, especially when other comorbid conditions are present.

Healthy lifestyle education should be available to all living donors.

Dyslipidemia

Dyslipidemia should be included along with other risk factors in donor risk assessment, but dyslipidemia alone does not exclude kidney donation.

Urine analysis for protein

A 24 h urine protein of >300 mg is a contraindication to donation.

Microalbuminuria determination may be a more reliable marker of renal disease but its value as an international standard of evaluation for kidney donors has not been determined.

Urine analysis for blood

Patients with persistent microscopic hematuria should not be considered for kidney donation unless urine cytology and a complete urologic work up are performed. If

urological malignancy and stone disease are excluded, a kidney biopsy may be indicated to rule out glomerular pathology such as IgA nephropathy.

Diabetes

Individuals with a history of diabetes or fasting blood glucose ≥ 126 mg/dl (7.0 mmol/l) on at least two occasions (or 2 h glucose with OGTT ≥ 200 mg/ dl (11.1 mmol/l) should not donate.

Stone disease

An asymptomatic potential donor with history of a single stone may be suitable for kidney donation if:

No hypercalcuria, hyperuricemia, or metabolic acidosis.

No cystinuria or hyperoxaluria.

No urinary tract infection.

If multiple stones or nephrocalcinosis are not evident on CT.

An asymptomatic potential donor with a current single stone may be suitable if:

The donor meets the criteria shown previously for single stone formers and current stone <1.5 cm in size, or potentially removable during the transplant.

Stone formers who should not donate are those with:

- (a) Nephrocalcinosis on X ray or bilateral stone disease and
- (b) Stone types with high recurrence rates, and are difficult to prevent

Malignancy

A prior history of the following malignancies usually excludes live kidney donation:

Melanoma, testicular cancer, renal cell carcinoma, choriocarcinoma, hematological malignancy, bronchial cancer, breast cancer, and monoclonal gammopathy.

A prior history of malignancy may only be acceptable for donation if:

Prior treatment of the malignancy does not decrease renal reserve or place the donor at increased risk for ESRD.

Prior treatment of malignancy does not increase the operative risk of nephrectomy.

A prior history of malignancy usually excludes live kidney donation but may be acceptable if.

The specific cancer is curable and potential transmission of cancer can reasonably be excluded.

Urinary tract infections

The donor urine should be sterile before donation; asymptomatic bacteruria should be treated pre donation.

Pyuria and hematuria at the proposed time of donation is a contraindication to donation.

Unexplained hematuria or pyuria necessitates evaluation for adenovirus, tuberculosis, and cancer. Urinary tuberculosis or cancer are contraindications to donation.

Acceptable donor renal function

Live unrelated donors

The current available data suggest no restriction of live kidney donation based upon the absence of an HLA match. An unrelated donor transplant is equally successful to the outcome achieved by a genetically related family member such as a parent, child, or sibling, who is not HLA identical to the recipient.

Determination of cardiovascular risk

The clinical predictors of an increased perioperative cardiovascular risk (for non-cardiac surgery) by the American College of Cardiology /American Hospital Association standards fall into three categories: major, intermediate, and minor.

All major predictors: unstable coronary syndromes, decompensated heart failure, significant arrhythmias and severe valvular disease are contraindications to live kidney donation. Most of the intermediate predictors: mild angina, previous myocardial infarction, compensated or prior heart failure, and diabetes mellitus are also contraindications to donation. Minor predictors: older age, abnormal ECG, rhythm other than sinus, low cardiac functional capacity, history of stroke, or uncontrolled hypertension warrant individual consideration.

Assessment of pulmonary issues

A careful history and physical examination are the most important parts of assessing risk. Routine preoperative PFT is not warranted for potential live kidney donors unless there is an associated risk factor such as chronic lung disease. Increased risk of post operative pulmonary complication is assoc with an FEV1<70% or FVC<70% of predicted, or a ratio of FEV1/FVC<65%.

Smoking cessation and alcohol abstinence

Smoking cessation at least 4 weeks before donation is advised based on recommendations for patients undergoing elective surgical procedures.

Cessation of alcohol abuse defined by DSM-3: 60gm of alcohol/day sustained over ≥ 6 months should be avoided for a minimum of 4 weeks to decrease the known risk of postoperative morbidity.

Components of the psychosocial evaluation of living kidney donors:

Sociodemographic history and current status

- Educational attainment, living situation, religious beliefs and practices, marital status, and employment.

Capacity

- Cognitive status and capacity to comprehend information; risk for exploitation by others for monetary or other personal gain.

Psychological status

- Presence of current and past psychiatric disorder, including mood, anxiety, substance use, personality or other serious disorders.
- Current and past use of therapeutic interventions (counseling and medications) for psychological or other stressors including sexual abuse, or for chronic pain management. Nature of coping skills to manage current or past life or health-related stressors.

Relationship with transplant candidate

- Nature and degree of relationship (if any) to transplant candidate; whether donation would impose expectations or perceived obligations.

Motivation

- Rationale and reasons for volunteering to donate; perceived coercion or undue pressure by others to donate.

Knowledge, understanding, and preparing for donation

- Awareness of short- and long-term risks for surgical complications and health outcomes; understanding of recovery and recuperation time; availability of alternative treatments for the transplant candidate.

Social supports

- Spouse or other significant family members' support for proceeding with donation; support from other sources (friends and employer).

Financial status and suitability

- Financial stability and freedom from current or expected financial hardship; availability of resources to cover expected and unexpected donation-related expenses; availability of disability and health insurance.

Marginal Donors:

Expanded criteria deceased organ donors (ECD) are a source of kidneys that permit more patients to benefit from transplantation. ECD is defined as all deceased donors older than 60 years and donors older than 50 years with 2 of the following: hypertension, stroke as the cause of death, or preretrieval serum creatinine greater than 1.5 mg/dl. The waiting list has become a “waiting to die” list, as 5% of patients on the kidney waiting list die each year.

The decision to use an ECD kidney is complex because there are data to suggest that these kidneys have a higher rate of primary non function, DGF, rejection, and a greater susceptibility to preservation injury, drug toxicity, and the effects of post transplant hypertension. In addition, ECD kidneys are believed to be more resource-intensive and costly. Moreover, the longevity of an ECD kidney is believed to be much shorter, with the half-life estimated to be 4 to 6 years compared with 8 to 12 years with a standard criteria donor kidney. However allocation of the ECD kidney to ‘marginal recipients’ improves outcome and reducing waiting time.³⁸

Post donation issues

1. Short-term issues like activity restriction, incisional pain
2. Long-term care like annual evaluation and emphasis on healthy lifestyle, review of medications and avoidance of nephrotoxic medications.
3. Effects of unilateral nephrectomy
 - a) Deaths before discharge - 0.03% (UNOS data between 1999 and 2002)
 - b) Short term effects like pain, bleeding, infections
 - c) Long term like proteinuria, development of ESRD, hypertension, pregnancy and pregnancy outcomes³²

Factors influencing Donor Availability

This is a neglected area where in the due to social and perception of the complications of donation by the donor, family members or even the recipient can affect the act of voluntary donation. In India, the Human Organ Transplantation Act of 1994 and its amendments discourages unrelated transplant due to ethical reasons and to avoid exploitation of the financially disadvantaged people. And with the increasing incidence and prevalence of diabetes and other non communicable diseases the availability of donors is restricted from an already limited donor pool.

As per the Human Organ Transplantation Act of 1994 and its amendments discourages biologically unrelated transplant due to ethical reasons and to avoid

exploitation of the financially disadvantaged people. This in addition to medical and other non medical factors affects the donor availability adversely.

Psychosocial reasons for donor non availability

In 1987 in the USA 25% of all renal transplantations were performed with living related donors, while in Europe only 11% of all transplanted kidney patients received a kidney from a living donor. In a study involving 139 patients in the Netherlands Sixty-six percent of all potential offers did not result in transplantation, approximately 35% due to immunological reasons, including ABO incompatibility and almost 30% due to medical reasons in the potential donor. In the majority of cases the medical reasons were due to some form of renal abnormality; 10% of all potential donors were excluded for this reason. The high incidence of renal disease of the potential donors could be due to genetic influences.

In another study that retrospectively addressed the effects of the organ donation process in 536 donors living related kidney donors the majority (69.5%) of the subjects volunteered to come without having been solicited. The parents were the recipients in the majority (93.1%) of the unsolicited volunteers. A substantial majority of the donors indicated that neither their families (85.8%), nor their friend (86.2%), nor the health care professionals with whom they had contact (93.7%) had attempted to influence their decision. Individuals were more likely to receive pressure from their family to donate if the recipient was a parent and while family pressure not to donate was substantially more

prevalent if the recipient was a sibling. The subjects who experienced pressure to donate from their friends notably more frequently reported donation to have been a financial burden.

It was apparent in the above study that in excess of 14.0% of the donors had experienced direct pressure, particularly not to donate, from their families or friends. This finding suggests the need to recognize the influence of the potential donor's social network, to provide those individuals with appropriate information on kidney donation, and possibly to include them in the decision-making process.

Sequel of donor nephrectomy:

In a recent involving 255 donors followed up for a mean duration of 12.2 ± 9.2 years the glomerular filtration rate (GFR) and urinary albumin excretion were assessed and it was found that the prevalence of hypertension, general health status, and quality of life is similar to that of persons who have not donated a kidney. The risk of ESRD does not appear to be increased among donors, and their current health seems to be similar to that of the general population. In addition, their quality of life appears to be excellent. The rate of change in the GFR did not appear to accelerate over time. The prevalence of hypertension and albuminuria in kidney donors were similar to those in controls who were matched for age, sex, race or ethnic group, and body-mass index, even two decades after donation¹².

AIMS AND OBJECTIVES

Aim:

To evaluate the patients with chronic kidney disease stage 5 (CKD 5) and their prospective renal transplant donors regarding:

1. The renal replacement choices made by the patients with CKD 5.
2. To assess the medical and non-medical factors that affect living related renal donor selection among prospective renal transplant recipient.

Objectives:

All the patients with CKD 5 attending the nephrology out patient department from December 2006 to November 2008 were prospectively screened and the patients with CKD 5 were interviewed in detail. And the prospective recipient and their respective donors are interviewed again on separate occasions. The factors studied are:

1. Demographic features of the patients and their prospective donors
2. Socio-economic status using modified Kuppuswamy's (urban) socioeconomic score
3. Reason for choosing a specific modality of renal replacement therapy.
4. Total possible number of first degree related donors.
5. Medical and non medical factors that is likely to affect the donor selection.

6. The reasons for withdrawal from the renal transplant program.

METHODOLOGY

Study Design:

The study was a cohort study on consecutive patients with chronic kidney disease stage 5 (CKD 5) who presented to the nephrology services of Christian Medical College, Vellore. The renal replacement options chosen by the patients and the medical and non medical factors that determine the living kidney donor selection were studied.

Setting:

The study was conducted among the out-patients of the department of nephrology, units 1 and 2 of the Christian Medical College (CMC), Vellore, South India which is a 2300 bedded tertiary care teaching hospital. Nephrology services are being offered for the last 35 years.

Subjects**Inclusion Criteria:**

- a) Subjects newly diagnosed as cases of CKD 5 based on history, calculated abbreviated MDRD (Modification of Diet in Renal Disease) estimated GFR (Glomerular Filtration Rate) equation.
- b) They had compatible ultrasonographic evidence of CKD 5.

Exclusion Criteria:

- a) The study excluded subjects who had been diagnosed to have CKD at CMC prior to the study period.

- b) The study excluded cases of renal insufficiency where the diagnosis of chronicity was in doubt and required verification by further investigations.

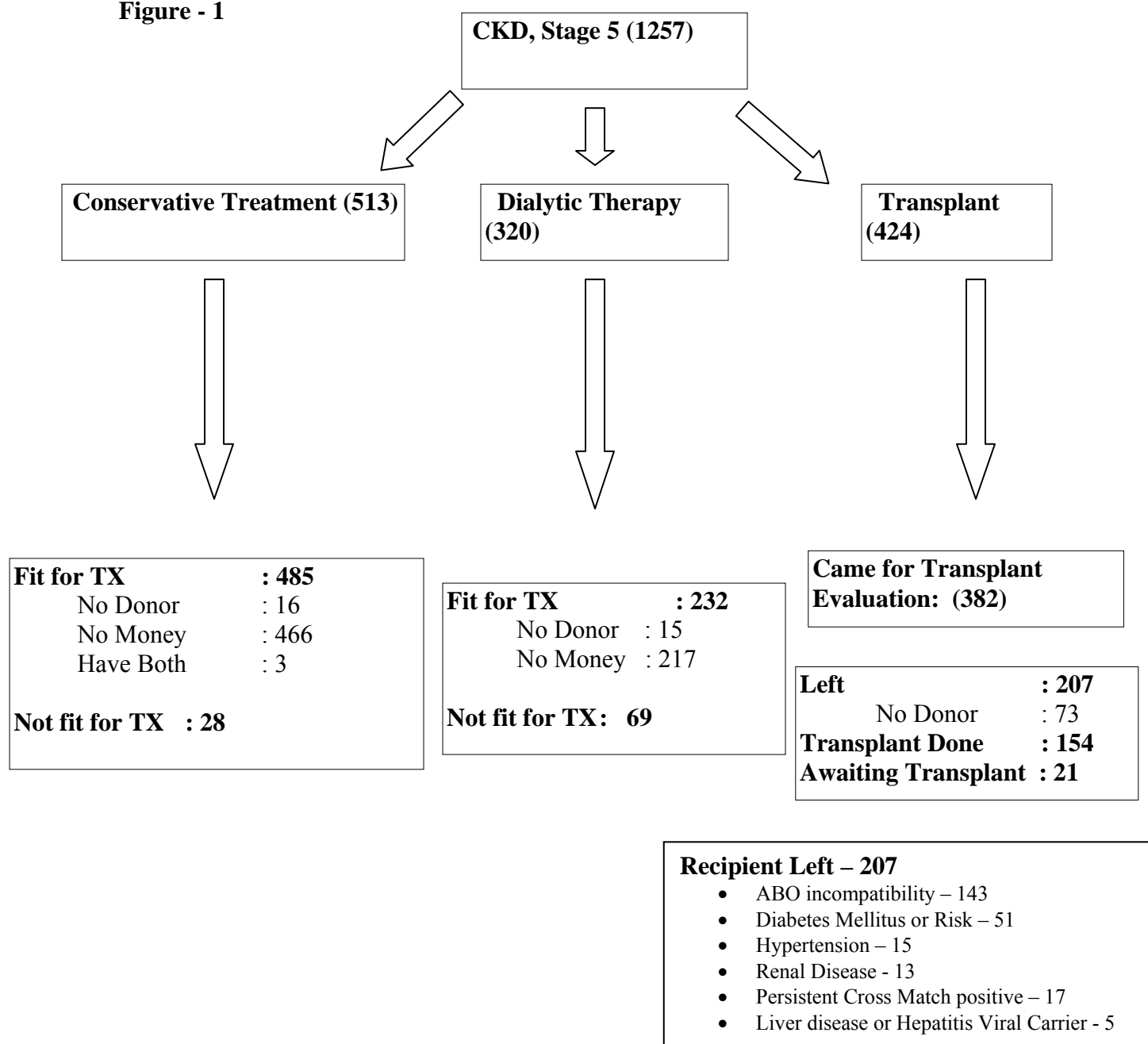
Evaluation:

Consecutive patients with CKD 5 presenting to nephrology services from December 2006 to November 2008 were prospectively enrolled upon making a diagnosis of CKD 5. The patients and the relatives were interviewed by the investigator with regard to the renal replacement options planned and the prospective recipients and their prospective donors were interviewed separately and the medical and non medical factors that could possibly have a bearing on the selection and rejection or withdrawal of a particular donor was analyzed. The data thus collected was then entered into an electronically compatible proforma.

Statistical Analysis:

Summary statistics and tests of significance (Chi square tests for categorical variables and student t tests for continuous variables) were calculated using SPSS version 14 software package.

RESULTS

RESULTS:**Choice or Renal Replacement therapy Chosen:****Figure - 1**

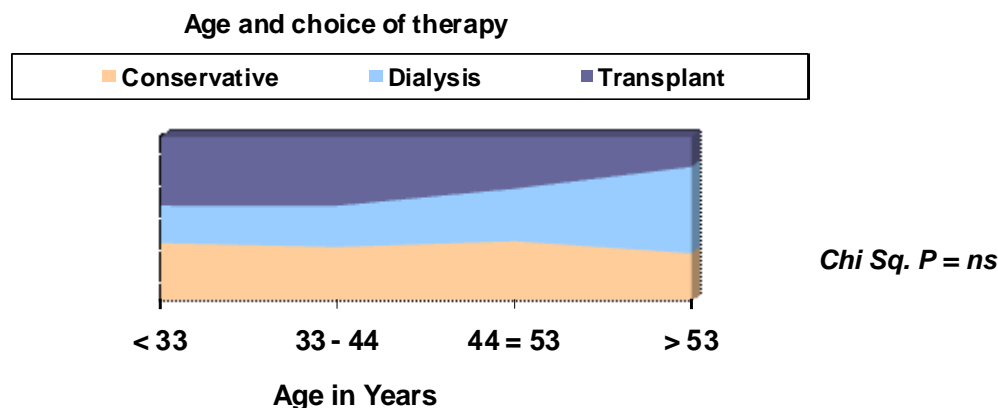
Out of the 1257 CKD 5 patients 513 (40.8%) had chosen conservative treatment and poor finances influenced the decision in 466 (96.1%) of the 485 patients who otherwise was fit for being a renal transplant recipient. Only 16 patients did not have a single donor as per the age criteria of > 20 years and < 60 years.

A similar trend was seen among the 320 (25.5%) patients who chose dialytic form of renal replacement therapy. Here 217 (93.5%) of the 232 patient fit to be a renal transplant recipient's decision was influenced by poor finances.

Of the 1257 patients with CKD stage 5, 424 (33.7%) chose renal transplant as their modality of treatment and of these only 382 (90.1%) came for recipient evaluation. Study of the prospective transplant recipients showed 73 (19.1%) of the 382 patients did not have a single donor and that contributed to 35.3% (73/207) of the prospective recipients who left our transplant program.

Figure – 2, Age and Choice of Renal Replacement Therapy

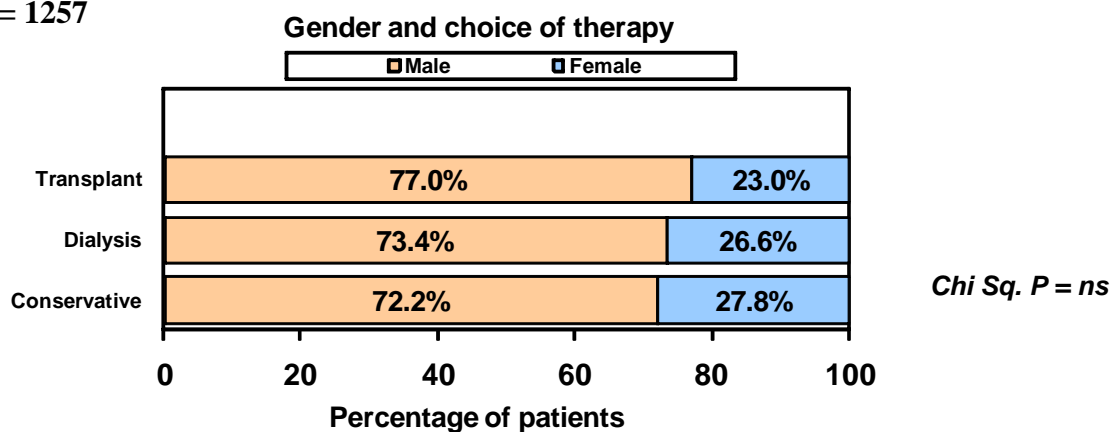
N = 1257



Though there was a trend towards older patient choosing maintenance dialysis as a modality of renal replacement therapy and younger people choosing renal replacement therapy it was not statistically significant. In addition, the number of patients choosing conservative treatment was not different across the various age groups suggesting age was not a major factor influencing the choice of therapy.

Figure –3, Gender and Choice of Therapy

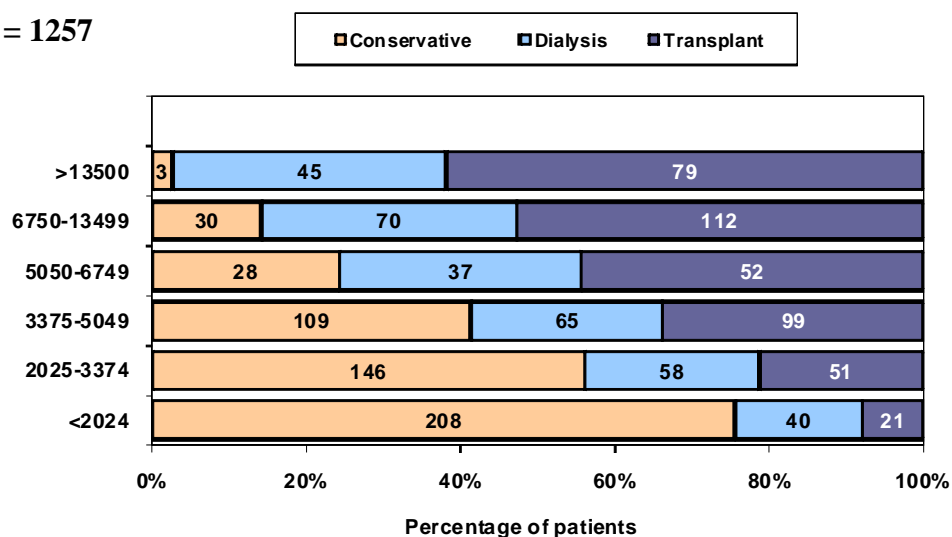
N = 1257



Similarly gender had no influence on the choice of therapy and the difference across the groups was not significantly different.

Figure – 4, Monthly Income and Choice of Therapy

N = 1257

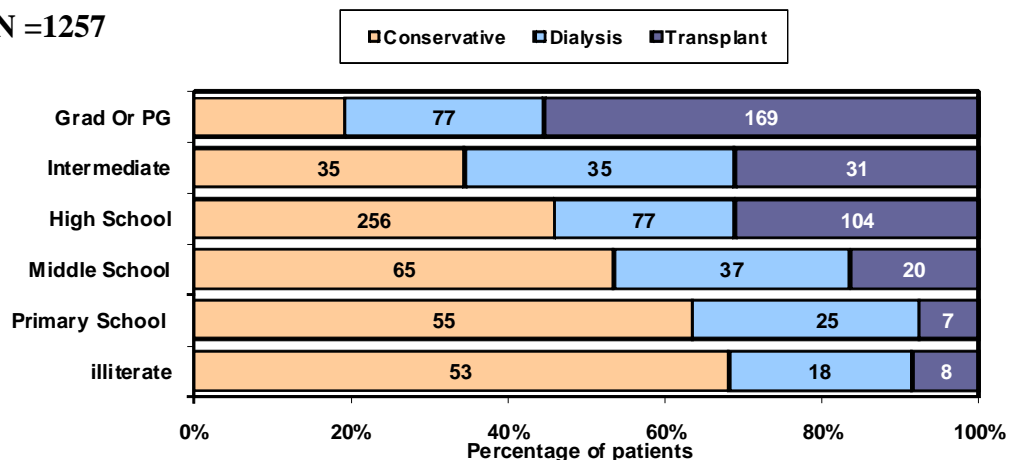


Chi Sq. P = 0.000

There was a significant difference in the monthly family income of the there treatment groups with higher income group preferentially opting for transplant and dialysis compared to the lower income groups.

Figure – 5, Education and Choice of Therapy

N =1257



Chi Sq. P = 0.000

Higher proportion of patient with better education chose renal transplant over the other modalities as shown in the above figure and the difference was statistically significant.

Demography of the Prospective Transplant Recipients

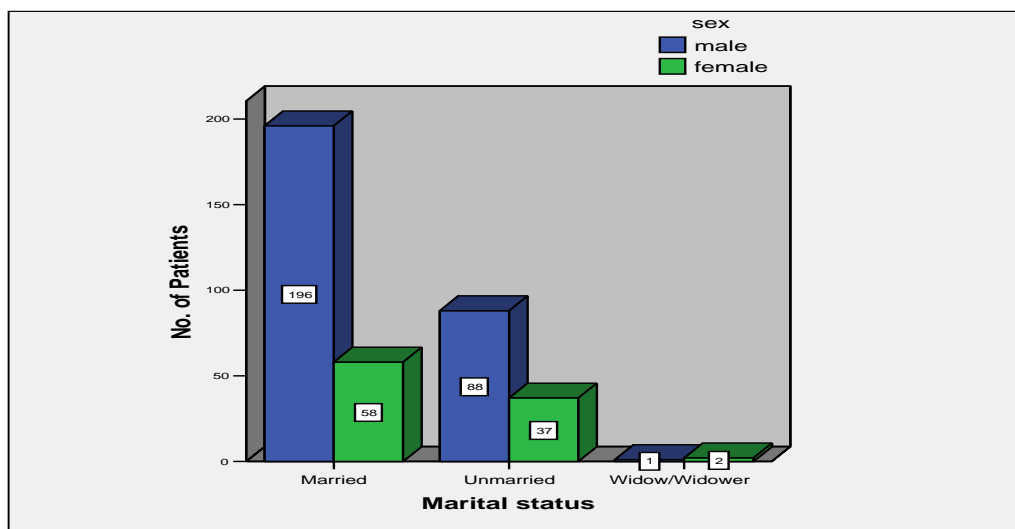
Table – 1, Age – Prospective Renal Transplant Recipients

Age Group N = 382	No. of Patients	Percentage
< 10	03	0.8
10-19	21	5.5
20-29	86	22.5
30-39	85	22.3
40-49	87	22.8
50-59	86	22.5
60-69	14	3.7

The mean age of the recipient who came for evaluation was 38.47 ± 13.02 years and the range was from 6 years to 65 years.

Figure – 6, Gender and Marital Status– Prospective Renal Transplant Recipients

N =382



The recipient population under study was predominantly male forming 74.6% of the cases (285 of 382 cases). As illustrated two-third of the recipients were married.

Socio-economic status:

Table – 2, Education – Prospective Renal Transplant Recipients

Level of Education N = 382	No. of Patients	Percentage
Illiterate	01	0.3
Primary School or Literate	06	1.6
Middle School Certificate	14	3.7
High School Certificate	56	14.7
Intermediate or Post High School Certificate	106	27.7
Graduate or Post Graduate	183	47.9
Professional or Honors	16	4.2

The majority of the prospective transplant recipients, i.e., 94.4% had a level of education better than high school certificate and only one patient was illiterate.

Table – 3, Occupation – Prospective Renal Transplant Recipients

Occupation N = 382	No. of Patients	Percentage
Unskilled Worker	34	8.9
Semi-skilled Worker	35	9.2
Skilled Worker	103	27.0
Clerical, Shop owner, Farmer	116	30.4
Semi-Professional	62	16.2
Professional	32	8.4

As per the modified (2003) Kuppusamy classification (urban) only 18.1% of the prospective transplant recipients were semi-skilled or unskilled workers, 24.6% were semi-professional or professional and the rest were skilled workers or were self employed or were doing clerical jobs.

Table – 4, Socioeconomic Status– Prospective Renal Transplant Recipients

Socioeconomic Class N = 382	No. of Patients	Percentage
Upper	29	7.6
Upper Middle	253	66.2
Middle	94	24.6
Upper Lower	6	1.6
Lower	0	0

None of the patient belonged to low socioeconomic status and 90.8% were either upper middle class or middle class.

Table – 5, Blood Groups – Prospective Renal Transplant Recipients & Donors

ABO Blood Group N =382	No. of Patients Recipient (Percentage)	No. of Patients Donor (Percentage)
O POS	193 (50.5)	132 (34.6)
A POS	69 (18.1)	25 (6.5)
B POS	95 (24.9)	56 (14.7)
AB POS	19 (5.0)	3 (0.8)
O NEG	4 (1.0)	3 (0.8)
A NEG	1 (0.3)	0 (0)
B NEG	1 (0.3)	2 (0.5)

Pos - Positive, Neg - Negative

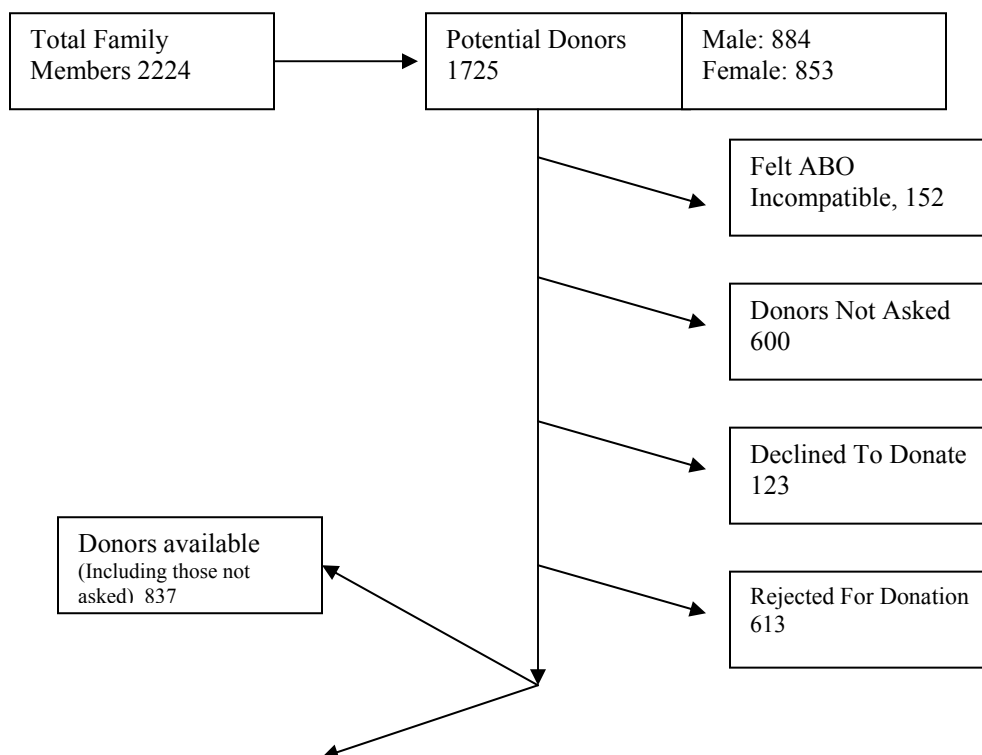
The commonest blood group in both the recipient and the donor population were O positive and B positive. The O positive blood group was seen in 50.5% of the recipients while it was seen in only 34.6% of the prospective donors.

Table – 6, Recipient Donor Relationship, N= 382

Donor Relationship to Recipient	No. of Patients	Percentage
Mother	81	21.2
Brother	75	19.6
Sister	63	16.5
Wife	47	12.3
Father	41	10.4
Cousin Brother	20	5.2
Son	14	3.7
Husband	11	2.9
Step Brother	8	2.1
Cousin Sister	6	1.6
Uncle	4	1.0
Unrelated	4	1.0
Step Mother	2	0.5
Nephew	2	0.5
Brother In Law	2	0.5
Aunt	1	0.3
Daughter	1	0.3

As our program strongly encourages first degree relatives to donate most of donors were near relatives. Mother was the donor in 21.2% of cases and brother, sister, father were donors in 19.6%, 16.5% and 10.4% respectively. Spouse came forward for donation in 68 (15.2%) out of 382 cases.

Figure – 7, Donor Tree



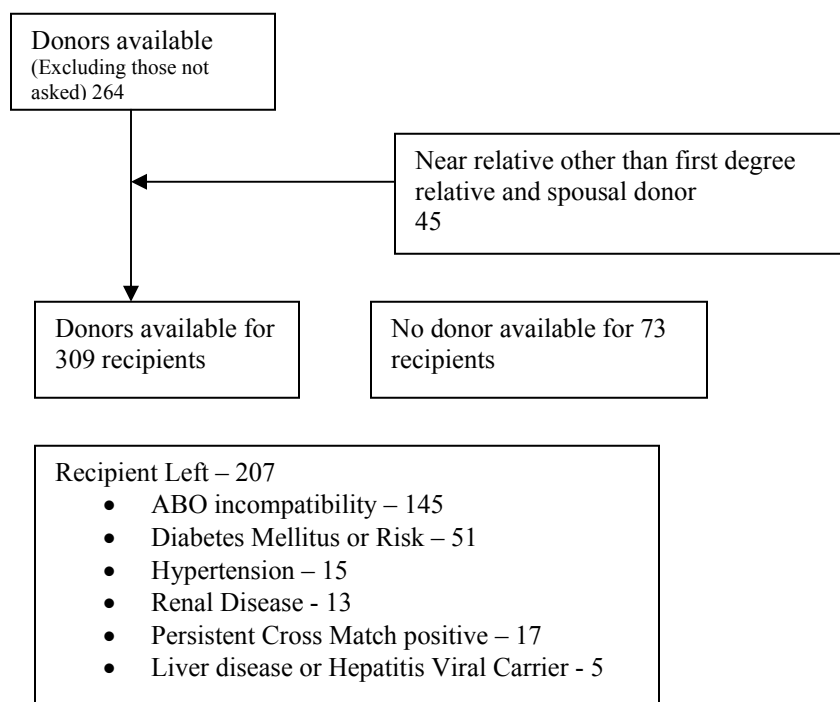


Table – 7, Requested To Consider Donation

N = 382	No. of Patients	Percentage
Recipient	113	29.6
Donor Came Forward	107	28.0
Recipient's Physician	98	25.7
Recipient's Spouse	27	7.1
Recipient's Family Member	37	9.7

The donor was first asked by the recipient in 29.6% of cases and the donor being a first degree relative in most instance came forward himself/herself in 28% of the cases. The recipient physician also had suggested the donor in 25.7% of the cases.

Table – 8, Attempted To Influence Donation

N = 382	No. of Patients	Percentage
None	336	88.0
Donor's Spouse	22	5.8
Uncle	11	2.9
Mother-in-law	9	2.4
Recipient's Physician	4	1.0

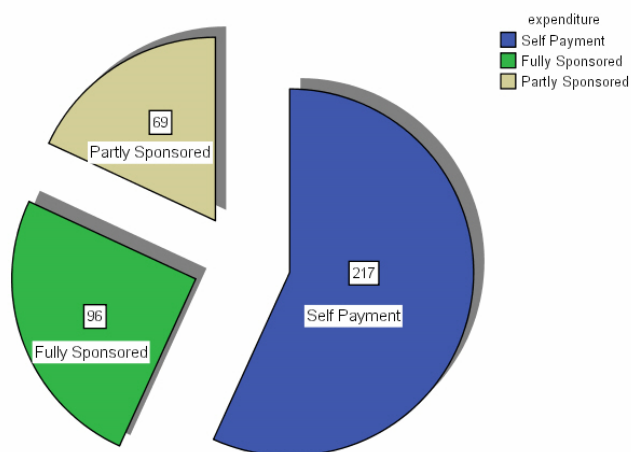
In 46 (22%) of cases there was at least one instance of an attempt to discourage donation and the donor's spouse was the commonest identified cause in 47.8% of the cases.

Table – 9, Reason for Declining to Donate

N = 71	No. of Patients	Percentage
Spouse Declined To Consent	36	50.7
No Specific Reason Disclosed	32	45.1
Spouse (Donor) Wanted to Take care of the Recipient	2	2.8
Horse Shoe Kidney	1	1.4

The commonest reason for a donor not coming forward to donate was due to spouse's negative coercion followed by no disclosed reasons for not donating. One case of donor withdrawing consent was due to horseshoe kidney in the donor.

Figure -8, Expenditure for Transplant, N = 382



Out of the 382 prospective recipients 56.8% (217/382) were not supported either fully or partly by governmental or non governmental institutions or by insurance.

Table – 10, Reason for Rejection of a Donor

N = 613	No. of Patients	Percentage
ABO incompatibility	281	45.8
Diabetes Mellitus*	147	24.0
Renal Disease	36	5.9
Proteinuria	17	
Renal Calculi	12	
eGFR# <60 ml/min	5	
Cortical Scar	2	
Hypertension**	34	5.5
Persistent Cross Match Positive	31	5.1
Liver Disease***	22	3.6
Ischemic Heart Disease	17	2.7
Unrelated Donor	10	1.6
Pregnancy	4	0.7
Sickle Cell Anemia/Trait	4	0.7
Family h/o ADPKD	4	0.7
Rheumatoid Arthritis	2	0.3

Thyroid Malignancy	2	0.3
Seizure Disorder	2	0.3
SLE	1	0.2
Autoimmune Hemolytic Anemia	1	0.2
Bronchial Asthma (Severe Persistent)	1	0.2
Mental retardation	1	0.2
Depression	1	0.2
Suspected Renal Cell Carcinoma	1	0.2
RHD Severe Mitral Stenosis	1	0.2

* DM - Diabetes Mellitus or Family history of Diabetes Mellitus in a first-degree relative

Abbrv. MDRD eGFR <60 ml/min

** Hypertension – Hypertension before 40 years or requiring more than 2 drugs at control of blood pressure

*** Liver Disease – Cirrhosis, HbsAg +, HCV antibody +, Non Alcoholic Fatty Liver, Alcoholic liver disease

The commonest cause was ABO incompatibility 45.8 %(218/613)

followed by diabetes mellitus or risk of diabetes mellitus 24% (147/613) and renal

disease 5.9% (36/613) in a prospective donor.

Table –11, Cause for Delay in Transplant Surgery

N = 382	No. of Patients	Percentage
No Delay*	34	8.9
Left Before HLA/Cross Match	95	24.9
Investigational Delay**	101	26.4
Money	39	10.2
Persistent Cross Match Positivity	31	8.1
CAG	16	4.2
PTCA	8	2.1
HLA could not establish relationship	9	2.3
Catheter Sepsis	8	2.1
HCV treatment	8	2.1
Uremic Cardiomyopathy	7	1.8
On ATT for TB	5	1.3
Nephrectomy	4	1.0
UTI	4	1.0

Evaluation for Debilitating Neuropathy	3	0.8
Valve Replacement	2	0.5
MRSA in Throat	2	0.5
Hypothyroidism Treatment	2	0.5
Epidural Hematoma	1	0.3
Communication Problem	1	0.3
Acute Hepatitis	1	0.3
Suspected Fungal Sinusitis	1	0.3

* No Delay – Transplant surgery within 30 days after starting evaluation for transplant

** Investigational Delay – Delay due to government procedures and not due to money or medical issues.

There was delay in getting a renal transplant surgery done in 91.1% of patients. The medical reasons contributed to 29.6% of the delay. And the commonest non medical reason was due to government procedures 26.4% (101/382).

Table: 12, Characteristics of patient who Left vs. who got Transplantation done/Waiting

N = 382	Transplant done / Awaiting	Left	p-value
Socioeconomic Status			ns
Upper	12	18	
Upper middle	109	142	
Middle	48	46	
Upper middle	5	1	
Marital status			ns
Married	122	132	
Unmarried	52	74	
Widow/widower	1	1	
Decline to donate			ns
Nil	149	164	
≥ 1	26	43	
Rejected			ns
Nil	74	79	
≥ 1	101	128	
No donor	21	62	0.00

Donor gender			0.03
Male	71	115	
Female	104	92	
Donor Marital status			ns
Unmarried	35	59	
Married	129	138	
Divorcee	4	8	
Widow/Widower	7	2	
Relationship to donor			ns
Mother	48	34	
Brother	33	42	
Sister	28	35	
Wife	24	22	
Father	16	25	
Others	82	49	
Requested to consider donation			ns
Recipient	56	57	
Came forward himself/herself	54	54	
Recipient's physician	45	52	
Recipient's spouse	8	19	
Recipient's family other member	12	25	
Attempted to influence decision	17	29	0.013
Perception of complication (Unsure or likely)	69	86	ns
Source of Finance			
Self	84	132	0.05
Sponsored	91	75	

Characteristics of patient who Left vs. who got Transplantation done/Waiting

The risk factors we identified among the prospective recipients who left our program were – absence of donor, presence of male donor, attempted coercion to donate and absence of financial support by the governmental or non governmental institutions either fully or partly.

DISCUSSION

Discussion:

Chronic kidney disease incidence and prevalence in India and worldwide is increasing and has become an important public health problem. Though life style modification, prevention and early detection of the of chronic kidney disease prolong life with reasonable quality.

The ever-widening gap between the numbers of people waiting for renal transplantation is all too familiar. In our country, our perception of the patient's choice of the modality of renal replacement therapy is that it is largely dependent on the means of financial support for transplantation followed by donor factors. We evaluated if that was really the case.

The mean age of the CKD 5 was 43.8 ± 13.3 years and the mean age of the patient who had chosen renal transplant as their modality was 38.5 ± 13.02 years. However, we observed that age did not have a significant influence on the modality chosen.

The males constituted 77.2% of the total population of chronic kidney disease, stage 5 population. This was comparable to the 69.6% as per the Indian CKD registry³³. Though it is tempting to believe that it may be due to socio-economic factors that more males had sought medical attention it is likely that the incidence of the disease per say is more in males. In a study by P. Jungers et al in a French urban area, the male female ratio was 2:1 after the age of 20 years onwards³⁴. In a hospital based data from south India showed a prevalence of 60-70% of males with CKD². However in an urban community based study from India only 48% of the population with any stage of CKD was males³.

There was no significant difference in the male-female ratio (70:30) in the three modality of therapy chosen by the patient suggesting that age and gender were not the major factors involved in choosing a particular modality of renal replacement therapy. Even in countries where the treatment is state sponsored males outnumber females. Some

of the gender difference in prevalence may be due to risk factors shared by cardiovascular disease and end stage renal failure, both of which are commoner in men.

There was a significant difference in the monthly family income, education status and socioeconomic status of the three treatment groups with higher income group and patients with better education opting for transplant and dialysis compared to the group that chose conservative treatment. Hence, patients with better socio-economical status more often chose dialytic form of therapy or renal transplantation. In our study, only 7.6% (96/1257) are fully sponsored and 5.5% (69/1257) were partly sponsored by governmental or non-governmental organizations for the treatment expenses. In 2004 poor Indians spent 40 percent of their income on health care; the rich spent about 2.4 %. Studies have shown that medical expenses were one of the three main factors pushing people into poverty³⁸. Hence it is not surprising that a large proportion of patients chose conservative treatment.

We did not evaluated the ‘health related literacy’ as a part of our study with instruments like Short Test of Functional Health Literacy in Adults (STOHFLA) which would have affected the decision making process. However the majority of the prospective transplant recipients, i.e., 94.4% had a level of education better than high school certificate and only one patient was illiterate.

As per the modified Kuppusamy classification (urban)³⁵ only 18.1% of the prospective transplant recipients were semi-skilled or unskilled workers, 24.6% were

semi-professional or professional and the rest were skilled workers or were self employed or were doing clerical jobs. None of the patient belonged to low socioeconomic status and 90.8% were either upper middle class or middle class.

The number of patients who chose conservative treatment, dialytic treatment and renal transplant were 40.8%, 25.5% and 33.7% respectively as against the Indian CKD registry data 75.1%, 22.5% and 2.5% respectively³³. Of the 33.7% of the patients who had chosen renal transplant as their modality of treatment 54.2% (207/382) had left for various reasons leaving only 13.9% of the initial population of 1257 with us for further evaluation. Such a large number of patients choosing renal transplantation as a modality can be due to two reason. The first is due to the fact that only 17.7% (68/382) patients were from the neighboring districts of Tamil Nadu, Andhra Pradesh and Kerala and a large number came with plans for renal transplant. The second is due to centre effect and patients come here particularly for transplant surgery.

As our program strongly encourages first-degree relatives to donate, most of donors were near relatives. Mother was the donor in 21.2% of cases and brother, sister, father were donors in 19.6%, 16.5% and 10.4% respectively. Spouse came forward for donation in 68 (15.2%) out of 382 cases. For the 172 patients who either had a transplant or were in the final stages of evaluation 70.9% were males and the females were the donor for 59.8% (103/172) of the recipients. Muthusethupathi et al from a state funded hospital from the state of Tamil Nadu, India had reported that two-third of their donor population was females and this had only marginally changed over the last 10 years³⁶.

And hence despite the increasing rates of transplant surgeries there is still exploitation of the female gender as a donor in our country. Unlike our country the donation rates in the western countries is close to unity. Interestingly for the 1725 possible age matched donors for all the 382 prospective recipients in our study the male- female ratio was 1:1 (884 male, 853 females).

The cultural factors are a possibility but we wanted to see if there are other factors that influence the choice of a female donor. The donor was first asked by the recipient to donate in 29.6% of cases and the donor being a first degree relative in most instance came forward himself/herself in 28% of the cases. The recipient physician also had suggested the donor in 25.7% of the cases. The female donors who donated either voluntarily came forward or were requested by their recipients to donate. Other family members or the recipient's physician did not influence their decision.

Among the donors who had come for evaluation in 46 (22%) cases there was at least one instance of an attempt to discourage donation and the donor's spouse was the commonest identified cause in 47.8% of the cases. The other family members constituted the rest.

The reported cause for some of the possible donors declining to come forward for donor evaluation was again the spouse refusing to give consent. And in the rest no reason was disclosed. This emphasizes the fact that the donor's spouse must be a part of the decision making along with the donor to allay some of the fears associated with donation.

In fact despite the donors voluntarily donating the organ, 40.5% were either unsure (38.7%) or felt it was likely (1.8%) to have complications per operative or long term morbidity like renal failure.

The commonest reason for a donor not coming forward to donate was due to spouse's negative coercion followed by no disclosed reasons for not donating. One case of donor withdrawing consent was due to horseshoe kidney in the donor.

For the 382 prospective recipients there were 1725 age matched donors with a 4.5 donors per recipient. Interestingly the male female ratio was approximately 1:1 (884 males, 853 females) among the total number of the donors. One third (34.8%, 600/1725) of the donor pool never was requested for donation, 8.8%, 152/1725 was thought to be ABO blood group incompatible, 7.1%, 123/1725 declined to donate and 35.5%, 613/1725 were rejected from donation. Despite 45 near relative other than the first degree relative and spousal donors consented to donate 19.1%, 73/382 prospective recipients did not have a donor.

We observed that compared to the group that successfully got a transplant done or were waiting for the transplant surgery the group of patient who left our centre without renal transplant had more number of prospective recipients who did not have a donor (62/207, 30%), had less female prospective donors (92/207, 44.4%) , were more likely to be coerced not to donate (29/207, 14%) and were less often were sponsored either partly or fully (75/207, 36.2%).

CONCLUSION

Conclusion:

In this study of patients with chronic kidney disease, stage 5 we made the following observations:

1. The renal replacement options chosen by the patients were – conservative treatment 40.8% (513/1257), dialytic therapy 25.5% (320/1257) and renal transplantation 33.7% (424/1257).
2. There was no significant difference in the age and gender among the three above groups.
3. The socio-economic status (SES) and its components – monthly family income, level of education and occupation were significantly different among the three groups with patients with higher choosing dialysis or transplantation as the modality of treatment.
4. Mother, sister and wife contributed as donors to 57.14% of the patients who actually got transplant done here.
5. The commonest cause of rejection of the donor from donating was ABO blood group incompatibility (45.8%, 281/382), followed by diabetes mellitus or a risk of diabetes mellitus 24% (147/382).

6. The donor came forward for organ donation at the recipient's request in 29.6% cases followed by from recipient's physician in 25.7%. The donor himself/ herself came forward in 28% of cases.
7. We observed negative coercion for donation in 12% of cases and 7.1% of the donors declined to donate.
8. 40.5% of the donors were unsure or felt I was likely to have per operative complication or morbidity like renal failure.
9. The risk factors we identified among the prospective recipients who left our program were – absence of donor, male donor, attempted negative coercion to donate and absence of financial support by the governmental or non governmental institutions either fully or partly.
10. The transplant expenses were fully sponsored in 25% (96/382) and partly sponsored in 18.1% (69/382) of patients.

ANNEXURE

a

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PROFOMA

r

CKD 5 TREATMENT MODAILTY CHOICE

Name: _____ **Age:** _____ **Sex:** M/F **Location:** _____

NKD: _____ **GFR:** _____ **ml/min (CG),** **ml/min (Abv.MDRD)**

SOCIO-ECONOMIC STATUS (Score Card)

(A) Education Score

- | | |
|---|---|
| 1. Professional or Honours | 7 |
| 2. Graduate or Post-Graduate | 6 |
| 3. Intermediate or Post-High-School Diploma | 5 |
| 4. High School Certificate | 4 |
| 5. Middle School Certificate | 3 |
| 6. Primary School or literate | 2 |
| 7. Illiterate | 1 |

(B) Occupation Score

- | | |
|--------------------------------|----|
| 1. Profession | 10 |
| 2. Semi-Profession | 6 |
| 3. Clerical, Shopowner, Farmer | 5 |
| 4. Skilled worker | 4 |
| 5. Semi-skilled worker | 3 |
| 6. Unskilled worker | 2 |
| 7. Unemployed | 1 |

(C) Family Income Per Month Score

Rupees

Score

> 13500

12

6750-13499

10

5050-6749

6

3375-5049

4

2025-3374

3

676 -2024

2

< 675

1

Total Score

26-29

16-25

11-15

5-10

<5

Socioeconomic Class

Upper (I)

Upper Middle (II)

Middle (III)

Upper Lower (IV)

Lower (V)

FAMILY DETAILS (Family Tree, identify AGE, SEX, MARITAL STATUS, POTENTIAL DONORS)

Fit / Not Fit (For Transplant)

Total Donors:

Actual:

Perceived:

Option Chosen: CONSERV HD CAPD TX

Reason for Choosing Conserv. Rx: No Donor / No Money / Not willing/Not Fit

Reason for Choosing Dialysis : No Donor / No Money / Not willing/Not Fit

Reason for Choosing Transplant : No Donor / No Money / Not willing/Not Fit

DONOR EVALUATION: Recip. Name : _____ **No:** _____

Donor Name: _____ **Age:** _____ **Sex:** _____ **H.No.** _____

1. Donor's Relationship to Recipient:

DONOR	GENDER		FAMILY RELATIONSHIP				
	M	F	SIBLING	PARENT	CHILD	COUSIN	OTHERS
POTENTIAL							
ACTUAL							

2. Donor's Decision to Donate:

Voluntary ☐

Requested to consider donation ☐

RECIPIENT	FAMILY MEMBER	RECIPIENT'S PHYSICIAN	OTHER HEALTH CARE PERSONAL	OTHERS
	?			

3. Attempted to influence decision: FOR Donation ☐ Against Donation ☐

4. If attempted to Influence Decision, Who?

RECIPIENT	FAMILY MEMBER	RECIPIENT'S PHYSICIAN	OTHER HEALTH CARE PERSONAL	OTHERS
	?			

5. **STEP I** Blood Group A B AB + -- AC PC Urea Cr

Urinalysis: Hematuria / Proteinuria +/ 2+ / 3+ / 4+

HIV -- / + HBsAg -- / + Anti-HBc -- / + HCV -- / +

6. <u>STEP II</u> Tissue Typing	Recipient	A	B	DR
	Donor	A	B	DR
7. Gynecology Examination				
8. Hep B Vaccine				
9. <u>STEP III</u> HB	TC	DC		
10. PT	PTT	Platelet	ESR	
11. Stool				
12. Uric Acid	Calcium	Phos		
13. LFT				
14. GTT Fasting	1 hr	1 ½ hr	2 hr	
15. Cholesterol	TG	HDL	LDL	
16. 24 Hour Urine Protein / Volume				
17. VDRL: Non –Reactive	Reactive inDilution			
18. Urine Culture				
19. ECG				
20. Chest X-Ray				
21. ECHO/ Cardiac Clearance				
22. <u>STEP IV</u> IVP				
23. <u>STEP V</u> CT Angiogram/ Urology Clearance				
24. Final Cross Match				
25 Any Other				

26. Mean Evaluation Period: _____ Days.

27. Reason for Delay: A. Investigational Delay: ☐ B. Patient Related Delay: ☐

a. HLA ☐

a. Medical illness: ☐

b. Cross Match + ☐

c. Others _____

b. Others _____

28. Early Complication after Nephrectomy: Pneumothorax ☐ Fever ☐ UTI ☐

Atelectasis ☐ Retroperitoneal Bleeding ☐ Wound Hematoma ☐

Bladder Overdistension ☐

29. At Discharge:

Mean Creatinine after Donation:

Mean Cr. Cl. after Donation:

Mean Arterial Pressure:

Protein/Cr ratio:

30. No. of Days in Hospital:

31. Reason for Longer stay:

☐ ☐

32. Decision to Donate affected by patient's perception of recipient's health? Yes ☐ No ☐

33. Mental Health Problem requiring professional help? Yes ☐ No ☐

34. Global assessment of effects of Donation by the donor.

Not Harmful ☐

Somewhat Harmful ☐

Adversely affected ☐

35. Relationship with the recipient post transplant-

No change ☐ Somewhat improved ☐ Substantially improved ☐ Worsened ☐

36. If provided the opportunity to reconsider the decision to donate

Definitely donate ☐ Probably donate ☐ Equivocal ☐ Unlikely to donate ☐

37. Expenditure of donor covered by -

Insurance ☐ Company ☐ Recipient ☐ Others: _____